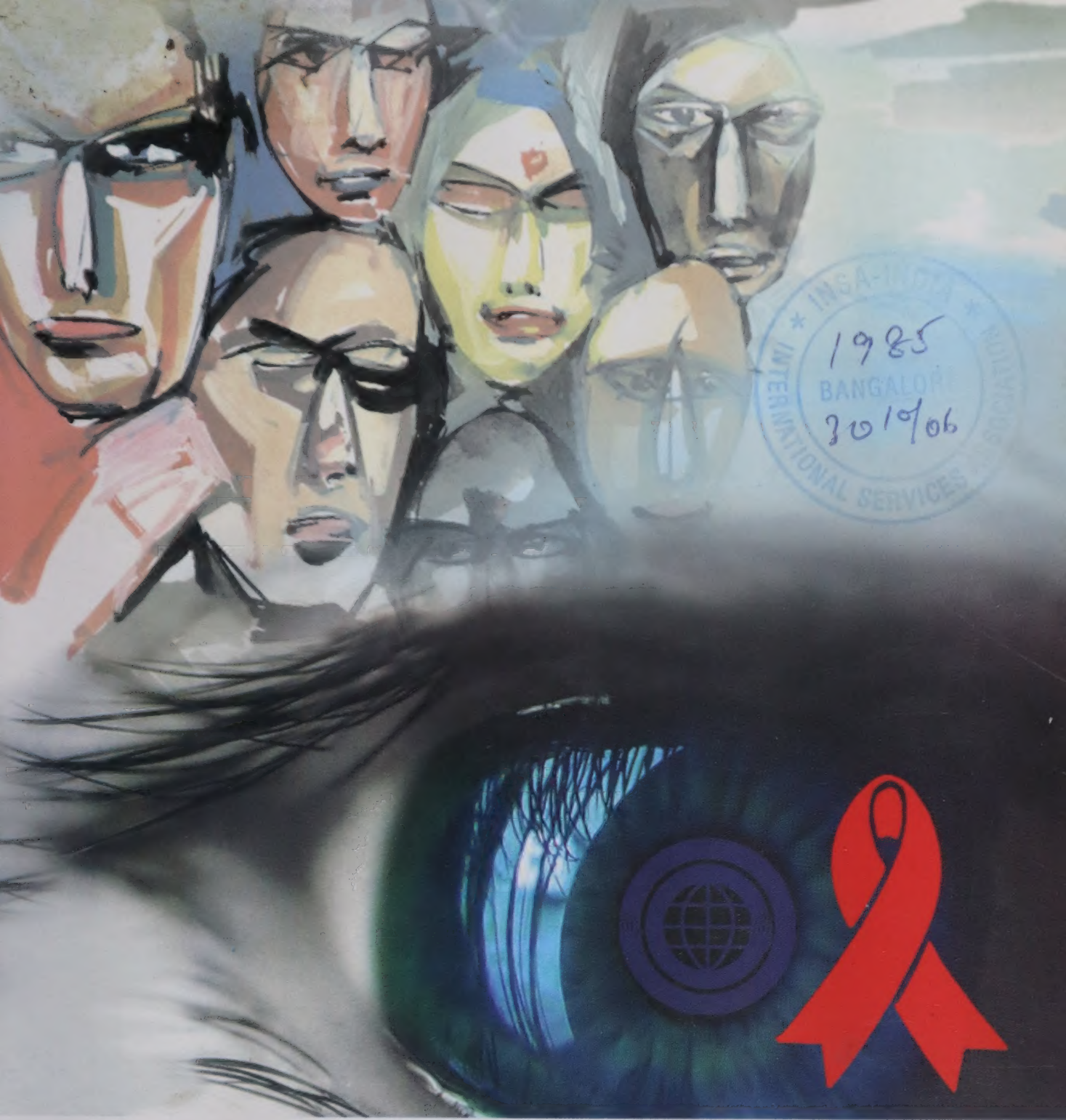
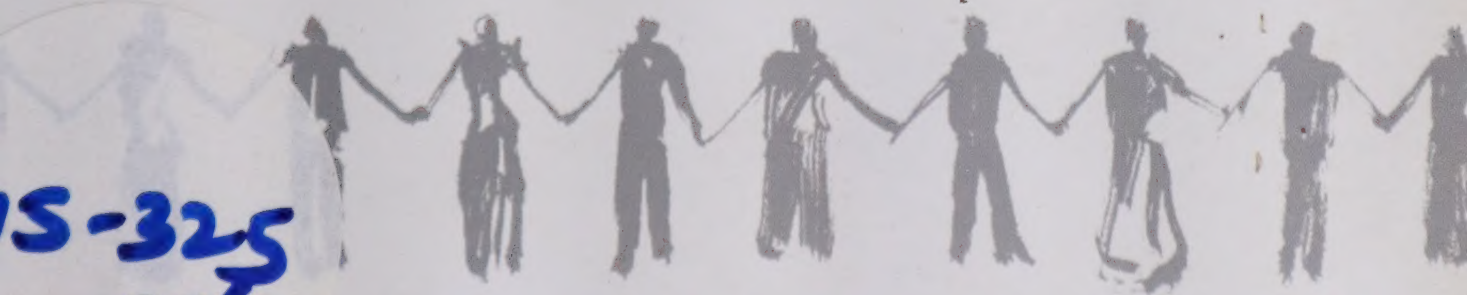


ENCOUNTERING HIV/AIDS



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Encountering [illegible]DS

Case Studies

January 2006

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Field Documentation	:	Janshi Rani and Ravikanth
Editors	:	Kalamani and Sucharita
External Editor	:	Gina E. Castillo, Novib
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Encountering HIV/AIDS

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Preface

Enough is known by now about the incidence and spread in India of HIV/AIDS over the last decade. Development agencies can no longer complacently view this problem as being in someone else's remit, whether these development agencies are in the public or non-governmental sectors. Centre for World Solidarity (CWS), from the non-governmental domain, has grown alive to the tremendous risks that HIV/AIDS problem holds for what it has achieved as an organization, and hopes to achieve in future, with the communities in the area of development. CWS has taken a while to realize all this and also that its own partners have been more alert in getting to act to counter the HIV/AIDS menace. CWS has finally made the vital decision that it should not be found wanting in doing its bit in the critical area of combating HIV/AIDS.

What is the way CWS is acting ?

First, it is equipping itself to play its role as a support agency for its partners active in HIV/AIDS control. This would also involve CWS motivating some of its hesitant partners into understanding the nature and extent of the problem and doing their part to help communities in this work. CWS now has a full-time trained and experienced woman staff member to guide CWS partners with all the necessary updated information in this regard.

Second, if there was ever an area where government and NGOs have to act together, HIV/AIDS is one. This is completely in line with the track record of cooperation over a hundred years between government and NGOs in all disaster situations, and HIV/AIDS risks constitute a

clear disaster situation, if in a non-dramatic form. Accordingly, CWS has entered into a collaborative arrangement with Andhra Pradesh Government for HIV/AIDS combating. The consistent encouragement and support CWS is receiving from NOVIB for this work also needs to be acknowledged.

Third, CWS should acquire for itself, and also propagate, a whole lot of sensitivities for it and its partners to play a difficult role in this very human situation. The present volume, giving a set of case studies, apart from conveying a sense of the reality to be handled, also maps the sensitivities needed for this challenging work.

The authors of the case studies, with Ms. A. Kalamani, Joint Executive Director, leading the team, deserve everyone's commendation for work that has been done diligently and with care as well as understanding. CWS hopes that this material will be found useful by all those who are handling the quiet crisis that HIV/AIDS is in India.

Secunderabad
16.2.2006

M.V. SASTRI
Convenor, CWS

Foreword

This is a series of life histories collected by Centre for World Solidarity (CWS). In 2005, CWS was just beginning to see how it would tackle HIV/AIDS in its work. Staff was hearing about it in the field. At the same time, Novib was searching for ways as to how it could better support its counterparts to tackle HIV/AIDS. CWS approached Novib and said that it wanted to mainstream HIV/AIDS into its work. As a first step, they proposed to document the life stories that they were hearing as they carried out their work. This collection is a product of their efforts.

In the following pages, you will read the stories of men, women and children whose dreams and lives have been altered forever because they discovered that they have HIV/AIDS. Most of these people are poor which means that, when they discovered that they had HIV/AIDS, they lost their homes and means to earn their livelihoods. In a lot of cases, they lost something even more precious: human contact. People - even their close relatives - refused to touch them for fear that they would become infected.

Today, there are more than 5.1 million individuals infected with HIV in India. The epidemic continues to shift towards women and young people. It has been estimated that 38% of adults living with HIV/AIDS in India are women. In 2004, it was estimated that 22% of HIV cases in India were housewives with a single partner. In fact, Indian women in monogamous marriages are increasingly susceptible to HIV (see Gillespie & Kadiyala 2005).[1]

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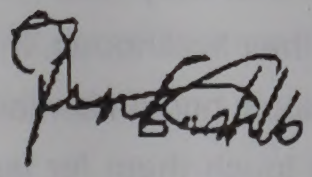
[1] 2005 Gillespie, Stuart and Suneetha Kadiyala, "HIV/AIDS and Food and Nutrition Security. From Evidence to Action". Food Policy Review 7

What statistics cannot tell is the human side of HIV/AIDS. This is what these life histories do. They all tell about how people contracted HIV/AIDS. These are very intimate and private matters. Tales of transmission are important and should be discussed. But these discussions should not lead to judgements about socially acceptable behaviour. It is too easy to think that some one who got it through a blood transfusion deserves more sympathy and assistance than someone who was having an extramarital affair.

As a donor, Novib would like the people who read these stories to think about stigma and what they can do to prevent it. We would not like curiosity about transmission to blind us from the acknowledgement that every person has a right to be treated with dignity and respect. We want curiosity to drive us to create a world without poverty, without HIV/AIDS, and without stigma.



Gina E. Castillo, Ph.D.
Novib Oxfam - Livelihoods Advisor

Abbreviations

AGD	-	Action for Girijan Development
AIDS	-	Accured Immune Deficiency Syndrome
ANM	-	Auxiliary Nursing Midwife
APPU	-	Association for HIV Positive People's Unity
APSACS	-	Andhra Pradesh State AIDS Control Society
Area Hospital	-	Government Hospital at Mandal Level
ART	-	Anti Retroviral Therapy
ARV	-	Anti Retroviral
BC	-	Backward Caste
CHAI	-	Catholic Health Association of India
CRSD	-	Centre for Rural Studies and Development
CWS	-	Centre for World Solidarity
DARE	-	Development Action for Rural Environment
DAWN	-	Development Action for Women in Need Society
FC	-	Forward Caste
FPP	-	Frontiers Prevention Programme
HIV	-	Human Immunodeficiency Virus
IEC	-	Information, Education & Communication
ITI	-	Industrial Training Institute
Mandal	-	Geographical unit of administration below the district level in Andhra Pradesh
Mason	-	Head of the labourers at building construction site
MSM	-	Men having sex with men
MTP	-	Medical Termination of Pregnancy

MYRADA	-	Mysore Rural Reconstruction and Development Agency
Mythri Clinic	-	STI clinics for PLWHAs run by HIV/AIDS Alliance
NACO	-	National AIDS Control Organisation
NEEDS	-	Nellore Environment and Economical Development Society
NGO	-	Non-Governmental Organization
Patta	-	A document confirming ownership/use and selling rates to the poor by the Government
PLWHAs	-	People living with HIV/AIDS
REDS	-	Rural and Environment Development Society
RDT	-	Rural Development Trust
RMP	-	Registered Medical Practitioner
SC	-	Scheduled Caste
SHIP	-	Society for HIV Infected People
ST	-	Scheduled Tribe
STD	-	Sexually Transmitted Disease
Tanda	-	Hamlet in Tribal Area
STIs	-	Sexually Transmitted Infections
TB	-	Tuberculosis
TT	-	Tetanus
UNICEF	-	United Nations Children's Fund
VCTC	-	Voluntary Counselling and Testing Centre
World Vision	-	International Development Organisation

ENCOUNTERING HIV/AIDS

Introduction

India has an estimated 5.135 million people infected with HIV/AIDS. It is the second highest national figure in the world after South Africa. One-ninth of the HIV infections in India duplicates at the rate of 0.91%. Heterosexual transmission of the epidemic accounts to 85% and the remaining 15% to blood transfusion and drug injections (particularly in North East and some metropolitan cities). The first case of HIV infection was detected at Chennai in 1986.

Since then, infections have been reported from all Indian States and its Union Territories. The epidemic shifts from high-risk to bridge populations (e.g. clients of sex workers, people who have sexually transmitted diseases (STDs) and partners of drug users) and then to the general population. An overwhelming majority of 89% is found in the age group of 15 - 44 years. Women alone constitute 29%. The alarming rise of infections in women comments on the low status of women in society and their associated power equations at household level. Gender inequality facilitates the spread of HIV and exacerbates its impact.

The burden of HIV/AIDS is being felt in the states affected early. HIV/AIDS is a generalized epidemic in Andhra Pradesh, Maharashtra, Tamil Nadu, Karnataka, Nagaland, Manipur and Mizoram. Among the badly affected states, Tamil Nadu continues to hold largest number of officially reported cases followed by Maharastra and Andhra Pradesh. With the rising incidence, Andhra Pradesh indicates the fastest HIV/AIDS prevalence states in India.

The Government of India launched a National AIDS Control Programme in 1987 to screen blood samples, blood products and do health education. In 1992, the National AIDS Control Organization

(NACO) was established to create awareness on HIV/AIDS. It formulated a policy for prevention and control of AIDS and established State-run AIDS Control Societies in the 25 States and 7 Union Territories.

Thus far, the spread of HIV/AIDS has been primarily addressed as a health and behavioural issue. Yet, the causes and consequences of the HIV epidemic are closely associated with wider challenges to development, such as poverty, food and livelihood insecurity, and gender inequality. In effect, HIV/AIDS tends to exacerbate existing development problems through its catalytic effects and systemic impact.

Given this, responses cannot be addressed only by HIV/AIDS specialists in the governmental and non-governmental sectors but by everybody, as well. In other words, a developmental rather than an AIDS-specific focus is critical to tackling the multi-sectoral complexity of the epidemic. It is the duty of non-specialists to respond and reach out to the People Living With HIV/AIDS (PLWHAs). Of late, due to the seriousness of the issue, many voluntary agencies have come forward to combat HIV/AIDS. The Government of Andhra Pradesh (AP) is also taking steps towards multi-pronged strategy to address HIV/AIDS.

Background

Recognizing HIV/AIDS as a development issue, Centre for World Solidarity (CWS) felt the need to mainstream the efforts to combat HIV/AIDS and its impact on the communities. Since mainstreaming HIV/AIDS has not gained much momentum in India, CWS felt the need to explore the various issues and dimensions of people living

with HIV/AIDS and decided to document the case histories of PLWHAs from different backgrounds.

The objectives of case studies are: First, to understand better how people were being affected by HIV/AIDS and on the basis of this for CWS to learn and to come up with a strategy at the organization and programme levels. Second, to document and share these findings with others so that they could make use of the information.

Eleven case studies have been drawn from among the general population through NGO partners working on HIV/AIDS and AP State Aids Control Society. The case studies can be grouped as follows:

- Urban youth
- Rural youth
- Organized urban sector (e.g. officials/persons holding public office)
- Rural sector (housewives and men employed in unorganized sector)
- Children living with HIV/AIDS
- PLWHAs from tribal region
- Migration/Trafficking locations
- Pilgrimage Centres

Attention was given to prepare the case histories of PLWHAs keeping class, caste, education, employment, age, gender, location, etc in view. The following features were documented:

- Awareness on HIV/AIDS
- Sources of infection
- Counseling
- Livelihood Status
- Care and Treatment
- Stigma and Discrimination
- Gender and Development Issues

A list of the questions that were asked can be found in Annex 1.

Great care and concern were utilized in collecting the case studies as well as their final presentation. Firstly, the names and identities of the people were kept confidential. Secondly, a non-judgmental approach was used at all stages. Finally, adequate care was taken to avoid stigma.

Summary

There are eleven case studies presented in this document. Four cases are from Anantapur and Guntur, two from Khammam and one from Hyderabad. The issues that emerged out of the case studies are summarized below:

An overview of the general characteristics of PLWHAs is presented below:

Sl	Background	Sex	Age	Category	Marital Status	Education
1	On Migration	M	36	SC	Yes	Tenth
2	Self Employed Individuals – Rural	M	40	BC	Yes	Third
3	Tribal Youth	M	17	SC	Yes	Diploma
4	Agricultural Labourer	F	40	SC	Yes	Illiterate
5	Self employed Individuals – Urban	M	36	SC	Yes	Tenth
6	Agricultural Labourer	F	24	FC	Yes	Illiterate
7	Semi Urban – Youth	F	16	BC	No	Seventh
8	Rural Youth Female Trafficked	F	20	SC	Yes	Illiterate
9	Infcted Child	F	9	BC	No	Fifth
10	Government Employed – Urban	M	40	SC	Yes	Seventh
11	Housewife	F	20	ST	Yes	Fifth

Out of eleven cases documented, six were women and five were men. The minimum age was nine years and the maximum was forty years. Five cases were in the age group of 20 years and below, and six were above 20 years. It is evident that in most cases the productive age group is infected with HIV. Six cases studied were from SC, three from BC and one each from ST and FC respectively. Except for one person who was a Diploma holder the remaining never studied beyond schooling. Three women out of six were illiterate.

The issues that emerged from the case studies were:

Awareness on HIV/AIDS: Prior to infection, PLWHAs had little or no awareness about HIV/AIDS. Once they knew something about it, many did seek more knowledge and information, through post counseling and through NGOs. However, access to information for women and girls is comparatively inadequate. Most of the women were unable to differentiate between HIV and AIDS. Children had no access to information/awareness due to their age and inability to understand. It was evident that there is no adequate knowledge on sex and sexuality among adolescents. The PLWHAs are mostly unaware of their rights.

Sources of infection: The major source of infection is unprotected sex with spouses, forced sex with minor girls, unprotected sex outside the marriage, and carelessness by the medical staff in testing the blood for possible HIV-contamination. Sexuality, sexual orientations and behaviours are greatly influencing the risk. Also poor nutrition, lack of hygiene and related factors are causes of biological vulnerability leading to various kinds of infections including HIV. This invariably happens to marginalised groups, and in particular the economically marginal.

Counseling: There is inadequate pre and post counseling. Even the doctors and medical staff lack sensitivity in providing adequate information and proper counseling to the HIV infected. At times, the behaviour of the medical staff further stigmatise PLWHAs. It is evident that the medical staff lack adequate training and expertise to deal with HIV/AIDS. Counseling centres are not widespread nor are they available to the poor.

Livelihood: The means of obtaining the necessities of life for the PLWHAs are very bleak. They lack financial resources. There are no specific programmes either by NGOs or government to address their livelihood needs. It is evident that lack of employment and livelihoods opportunities to PLWHAs makes them dependent on others and this makes them more vulnerable. They migrate in search of employment and anonymity fearing stigma and discrimination. The expenses to procure nutritious food and treatment hits upon the savings of the family and in many cases, forces them to sell their assets, properties etc. PLWHAs sink into deeper poverty and insecurity. There is no safety net or medical coverage.

Care and Treatment: The public health service is inadequate and not within the reach of PLWHAs. The availability of ART is currently inadequate. There is no diagnosis on when a person should be on ART. There is limited access to nutritious food, care and treatment. Also, desperation forces them to seek treatment in the unregulated alternative medical sector with disastrous consequences.

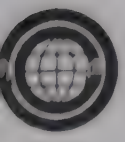
Stigma and Discrimination:

- The PLWHAs are disowned by their loved ones
- Many do not disclose due to fear of stigma and discrimination
- When a man is infected, his wife and child are ostracized

- Disclosure is not necessarily the option that the infected resort to. Non-disclosure and migration to protect the anonymity has been one of the common tendencies
- HIV/AIDS is associated with certain behavioural codes that had been stigmatized before the spread of the epidemic, e.g. sex between men and sex workers etc.
- With stigma and discrimination PLWHAs no longer feel part of the community. Therefore, it becomes even harder to provide them with the services and support that they need.

Gender and Development Issues: Gender inequality is one of the driving forces behind the spread of HIV. Access to information, knowledge, training etc is strongly determined along gender lines, and as a result men tend to be better informed than women. Low-income, income inequality, and low status of women are also associated with high levels of HIV infections. Women are vulnerable in HIV/AIDS affected households. Poverty, tradition and social pressure prevent women from voicing who should be their marriage partner and enjoying "safer-sex" practices. It is usually men and not women who determine when and how often to have sex, and whether a condom is used. Generally, it is men who have multiple sexual partners, and transmit the infection to their partners. Also, women living in abusive, violent relationship experience physical, verbal, emotional, psychological and sexual risk of HIV.

Thus poverty is playing a major role in HIV transmission pushing the poor communities into abject poverty and some non-poor into poverty. Further the behavioural patterns/attitudes are posing a great risk of HIV infections. While the search for economic betterments in many cases leads to increased migration the chances of multiple and casual



partners also increase. The condition of poverty makes AIDS education difficult especially where literacy levels are low and inaccessible to mass media, health and education services. Poverty and gender are inextricably intertwined. Alarmingly, it is the poor women who are most susceptible to HIV infections as they are unable to protect themselves from infected husbands.

The other major issues leading to increase in the HIV/AIDS infected are:

- Infant mortality, child marriage, child labour and lack of education to girl children
- Remarriage of women – still not accepted by family and society in certain communities
- Severe drought and other calamities
- Girls become vulnerable to trafficking and are forced into prostitution
- Denial of property rights to women and girl children
- Violence against women, discrimination, gender-based inequalities, prostitution - are all social issues that increase the risk to women and girl children
- Absence of economic opportunity for young women extremely diminishes their chance to exert greater control over their lives, have better access to health and information on sexually transmitted diseases
- The plight of orphaned children is unimaginable and they are left to the fate of their grandparents or siblings. These children are exposed to physical exploitation, abuse and lack of health, education and social services.

- Women, particularly young women, become targeted population in many AIDS education programmes whereas there is minimal attempt to educate men. There is inadequate attention given in these programmes on educating men on the practice of safer sex and sexual behaviours.

Lessons Learned

The documentation of the above case studies has helped CWS to understand better and deeper the various dimensions of HIV/AIDS and PLWHAs. The staff involved in documenting these case studies have definitely learnt a lot and become highly sensitive in using the right kind of language. The findings have reconfirmed to CWS the importance of mainstreaming HIV/AIDS internally through work place policies and externally in its programmes. Moreover, it has helped us to see the importance of lobbying with government for multi sectoral collaboration since we believe that the epidemic should be addressed as a cross cutting issue and as a shared responsibility by all concerned. For example, it might be important to lobby for the creation of an infrastructure that can concurrently expand networking of healthcare, education programs and community participation. Also, there is a real gap in appropriate IEC materials for women, youth, and children to increase awareness, community care and support. The findings can help us to plan appropriate developmental interventions to overcome poverty and economic problems of the PLWHAs particularly women.

A. Kalamani G. Sucharita

Secunderabad **A. KALAMANI** **G. SUCHARITA**

29.1.2006

Case Study One

Profile of the Person

Name	:	Rajaiah
Age	:	36
Sex	:	Male
Caste	:	Scheduled Caste
Religion	:	Hindu
Marital Status	:	Married
Education	:	Tenth Class (discontinued)
Place	:	Koulepalli Village, Kadiri Mandal, Anantapur District

Born to illiterate parents at Koulepalli in Kadiri mandal of Anantapur district in 1969, Rajaiah is the last child in a family of five. He has three sisters and one brother. Both parents work as agricultural labourers. Except for Rajaiah no one in his family went to school. His father enrolled him in a social welfare hostel in first class in 1978 in Kadiri town. He was a hosteller until his tenth class in 1988.

When his father died in 1985 at the age of 55, the burden of the family fell on his mother. Earlier, the eldest son had joined the naxalite movement and cut off all his contacts with the family. All his sisters were married off by then. His brothers-in-law drove auto rickshaws and sisters sold vegetables. His mother worked hard to feed the family, while Rajaiah indolently sat at home as he failed to clear school final examinations.

After a year, perturbed by his mother's admonishment for not working, he left Anantapur in 1989 without informing anyone. He searched every nook and corner of the town to get employed. Three days passed

and he did not find any employment. When the little money he had brought from Kadiri was spent, he decided, as the last effort, to pull a cycle rickshaw.

Luckily, days were passing off happily for Rajaiah as he was earning three to four hundred rupees a day. Within few years, he managed to save Rs.10000 and deposited the same in the local Post Office. Then the era of auto rickshaws came. The public preferred auto rickshaws to cycle rickshaws as they were both faster and cheaper. This new development posed a threat to the very livelihoods of all cycle rickshaw pullers in Anantapur town and several rickshaw pullers, including Rajaiah, took to auto rickshaw driving.

Months passed and Rajaiah became ambitious to earn more money. Not content with the earnings that he was making as an auto rickshaw driver in Anantapur town, he wanted to improve his financial situation. He heard from fellow drivers that auto rickshaw drivers in Tirupati town were making more than their counterparts in Anantapur, as Tirupati is a world famous pilgrim center. So, he moved to Tirupati.

In Tirupati, he bought an auto rickshaw for Rs.9000 from his savings. He started earning six to seven hundred rupees a day. The influx of money, afforded him to spend on pleasures. He frequently went to Puttur, Nagari, Sri Kalahasti etc in the weekends to meet his sexual desires.

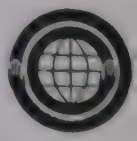
In the first half of 1997, Rajaiah had run his auto rickshaw over a boy causing serious and multiple injuries to him. Rajaiah had to sell his auto rickshaw to pay for the boy's hospital expenses. After the incident, he did not intend to stay in Tirupati and returned to his native village Koulepalli. He did not even work for six months there.

Meanwhile, his family members forced him to marry for fear that he might leave home without informing. He married Rajeswari, a 12-year old girl from a close relatives' family. Rajeswari was illiterate and quite naïve. At the time of marriage, Rajaiah had no job or source of income. However, the bride's parents and his family were hopeful that Rajaiah's auto rickshaw driving skills would provide some opportunity.

Rajaiah and his wife were totally dependent upon his mother's earnings. After a year, one day, he was down with fever and it continued for three months. He visited several doctors and saw various specialists but in vain. After three months strangely the fever spells disappeared. A month later he had diarrhea. Then he went to Kadiri Area Hospital to get examined. There, he was told that he had Tuberculosis (TB).

For about eight months, he took medication and got cured of TB. But he continued to lose a lot of weight and had run down from 75 to 50 kgs. He quarreled with his mother and sisters for not recommending a good physician. His mother and sisters gave him Rs. 3000 and told him to go to hospital or doctor of his choice and get cured. By then, his wife became pregnant.

In early 1999, he went to Government Hospital in Chennai and had a thorough medical examination. There, he was tested positive for HIV. When the doctors told him the status he did not even have a clue of what it was. The only thing he knew was that HIV/AIDS is a fatal disease. He never thought that he would get infected with it. He wanted to commit suicide, but held back, only to live for his wife and unborn child.



He went through counseling and doctors told him that there was nothing to worry about and advised him to eat nutritious food and about safer sex practices. They briefed him on how HIV spreads and also about the coping mechanism. They gave him courage to live. Consoled by the doctors' words, Rajaiah returned to his native village with a glimmer of hope in his heart. Back home, he did not utter any word about his health status. He told his family and neighbours that he was acutely suffering from TB. He even concealed it from his pregnant wife.

In July 1999, Rajeswari gave birth to a baby boy. In the year 2000, Rajaiah went to Tirupati Government Hospital with all his health reports. His family members also accompanied him. The doctors scanned through his reports and advised him to get admitted immediately. He was admitted in the AIDS ward.

Doctors in the hospital briefed his mother and sisters about his health situation. They told them that he would not live for more than a year. Their advise was to keep him, his wife and their baby in isolation. They warned the family members that they should not touch him. Rajaiah was astonished on hearing the shocking news. He shouted in deep anguish at the doctors and the other medical staff who treated him as untouchable. Whenever they came close to him, they used hand gloves and facemasks.

After a week, Rajaiah along with his family members, returned to his native village. He was quarantined along with his wife and son, in a house at the outskirts of the village. When the villagers asked his mother and sisters about this, they told that since he was suffering from acute TB, doctors at Tirupati advised them to keep the family in isolation for fear of infection. They even insisted that fresh air and

natural environment at the outskirts of the village would be better for Rajaian's health.

Every day his mother and sisters used to take food and visit Rajaiah and his family. They were careful not to touch them. Irked by the behaviour of the family members, Rajaiah once tried to commit suicide by consuming pesticide. His wife prevented him and begged him to stay alive for the sake of her and their son. She was taking care of him very well though other family members kept distance. However, she did not have any awareness on HIV/AIDS. Her husband told her that he came into contact with HIV when he practiced unsafe sex prior to marriage. She, however, understood that her husband was suffering from acute TB and thus he needed to be kept in isolation.

One day, Rajaiah read an article in the newspaper about Kerala ayurvedic medicine that offered permanent cure to HIV/AIDS. When he told his wife about this news, she sold her jewelry given by her parents and gave him the money. Rajaiah and his family went to Kerala. The ayurvedic doctor prescribed a medicine that cost him Rs. 6000 a month and that it had to be consumed for three months. With no delay he paid Rs.18000, to the ayurvedic doctor. After taking the medication for a month, he did not get fever or diarrhea. But the following month, even though he was consuming the medicine, fever and diarrhea recurred.

At this point of time, he met a doctor claiming that the medication that he was taking actually increased the problem. Rajaiah demanded his money back from the doctor. The doctor calmed him down and prescribed another medicine. After taking the new medicine, he began to feel normal again. For almost a year after, he did not experience any opportunistic infections.

A year later his problems resurfaced. This time he went to Tirupati along with his wife and son and got admitted in the Government Hospital. By this time, his family members - mother, brother and sisters stopped visiting him and his family.

One day a development activist from an NGO based at Tirupati met him in the hospital and assured him that there was help available. She took photographs of him, his wife and the son, and invited him to one of the organisation's monthly meetings. She also gave him 15 Kgs of grains every month continuously for three years. When Rajaiah left Tirupati for his native town, the aid ceased, as the place in which he lived did not fall in the jurisdiction of that NGO.

He became totally dependent on his wife and did not have strength to take up any kind of job. Even when he did light work, he vomited and was unable to bear the strain. The family's source of income came from his wife's earnings. When he was unable to pay the rent for five months, the landlord sold off all their belongings such as the television and drove them out of house. When he begged his mother with tears, she gave him one room, which was allotted to her by the District Administration under SC/ST quota. When his family moved in, his mother moved to Hyderabad to live with her daughter. When he went to his sisters for some utensils, he was told that they considered him to be dead. They refused to touch him and finally stopped seeing him.

Very recently, when he suffered from severe vomiting and diarrhea for 15 days continuously, he resorted to begging at the bus stand. He took the money, and went to Tirupati for treatment. His wife went to work and earned a paltry sum of Rs. 150 a week. His in-laws being poor and were not in a position to look after the family of Rajaiah.

They believed that their son-in-law had been ailing from T.B. and was on the verge of death.

Rajaiah's health was deteriorating. Very frequently he suffered from vomiting, diarrhea, boils on the skin, face etc, until 2000. He stopped having sex with his wife, when she was tested negative in 2003. His wife is just 18 years old at present.

Neither Rajaiah nor his family revealed to the world about his health status for the fear of being ostracized. He grieved that when his mother and sisters were unsympathetic he could not expect support from the society. He lamented that the medical staff, at the Government Hospital, Tirupati should have treated him better. However, he opines that because he has not revealed his health status to people, he was not facing any discrimination.

Unable to bear the strain of work he had totally stopped working. At one point, he even begged for money to undergo treatment. He is now totally dependant on his wife's earnings for everything, including food and medication. He has experienced a sea change in his life ever since he was tested positive: from being a high earning auto rickshaw driver he has been reduced to begging.

Prior to contracting HIV, he knew nothing about it. When he heard about it from friends he thought that it-is-somebody-else's disease but-not-his. He said that had he known about it, he would have practiced safer sex. Counseling from the Government Hospital, Tirupati, helped him gaining a lot of knowledge. He now thinks that prevention is the best method. Rajaiah understands that HIV/AIDS is not contagious, and does not spread through sharing towels, toilets, food etc. He is now able to describe the symptoms of AIDS, the difference between HIV and AIDS.

He opined that the only way of tackling this stigma is to educate society about HIV/AIDS particularly the medical staff. He expresses the need for the medical staff to be sensitized so that they can treat people living with HIV/AIDS better.

Rajaiah had never been a part of PLWHAs network. Nor does he know about the rights of PLWHAs. He refuses to be a part of PLWHAs network because of the fear that people will come to know about his status. He prefers to maintain absolute confidentiality about his health status, except to the doctors, NGOs and other aided voluntary organizations.

Rajaiah travels to Tirupati to acquire ART from the Government Hospital. As far as his medication and needs are concerned, Rural Development Trust (RDT) in Anantapur provides antibiotics for opportunistic infections.

Rajaiah counts on the government and organizations working on HIV/AIDS for nutritious food, drugs and suitable work. He wants to live in a world free from discrimination. He shared his views that his fellow PLWHAs are facing discrimination in the society and hence there is great need to educate the society. He expresses a desire to serve and care for his fellow PLWHAs.

Case Study Two

Profile of the Person

Name	:	Ramana
Age	:	40 years
Sex	:	Male
Caste	:	Backward Caste
Religion	:	Hindu
Marital Status	:	Married
Education	:	Third Class
Place	:	Bandarugudem Village, Manuguru Mandal, Khammam District

Ramana was born in 1966 in Lijalraopet in Khammam district. He is the second child in the family of six children. He has three brothers and two sisters. His father, Ramanatham, was a carpenter. He is now about 80 years old and mother, Venkatanarasamma, aged 68 is a housewife. All the family members depend on carpentry for their livelihood: Ramana is a carpenter and his sisters have been married off to carpenters. They all reside and work in Khammam district. No one in Ramana's family studied even up to school final, as there were too many financial constraints. After dropping out of primary school, he started helping his father in carpentry. Till the age of 25, Ramana worked as an assistant to his father. Then, he started working independently. He procures orders from furniture shops and work on it. He charges only for labour. He tried to put up his own shop, but it needed huge capital to invest. So he stepped back and concentrated on procurement of orders.

He married Mangamma in 1985 at the age of 19. His wife was just 16 then. The couple has two children, a daughter and a son, aged 18 and 10 years respectively. Since Ramana could not study further he determined to send both his children to school at any cost. His son is presently studying in sixth class. Ramana got his daughter married off after her school final, in April 2005, to an ITI who runs a flourmill.

In his early youth, Ramana had multiple partners and practiced unsafe sex. He continued it even after marriage. However, he stopped this when his son became one year old, i.e. after four years of his marriage. After an year, at the age of 24 in 1990, Ramana was casually introduced to a person named Suresh, by a common friend. After two months of friendship one day, Suresh asked Ramana whether he is interested in anal sex with him. Ramana was shocked as he never heard about MSM and found the situation strange to imagine. He politely refused and left the room immediately. But their friendship continued.

After a month Ramana went to Suresh's house when he was alone. Suresh served sedative mixed alcohol to Ramana and made him unconscious. Suresh performed anal sex with Ramana. When he awoke Ramana felt cheated and protested. Suresh consoled Ramana. Since then Suresh and Ramana would occasionally meet and have sex. The friendship went on for four years. One day, Suresh met with an accident and died. During the four-year friendship with Suresh, Ramana developed contacts with MSM group of eight residing in and around Manuguru. After the death of Suresh, he never visited the MSM group for almost a year. Later, he got close to person named Bhikshumaiah and Ramana had sex with him for nearly ten years. Bhikshumaiah is married and has children.

Ramana and his male friends occasionally used to go to a Government doctor in Kothagudem for regular check-ups. Doctor advised Ramana to undergo blood test for a possible detection of HIV. When he underwent the test, he was found positive for HIV. For almost a week, he could not recover from the shock. The doctor consoled him and informed him that nutritious food is what he required at the moment. Ramana did not reveal to any of his family members. He, however, shared this with his friend Bhikshumaiah, who consoled him and ensured that both could go for a check up again to confirm it. But it appeared that, they have not gone for another test.

Ramana came to know of his status only a month ago. From that day he started using condoms with his wife. When he came to know of his infection, he wanted to commit suicide, but could not, as his son is too young. He did not reveal this to anybody fearing stigma, nor did he send his wife for testing. So far, he did not develop any serious infections. Once he got itching and rashes on the skin for which he went to the Government hospital and got treated. His present health status is good. Sometimes, he used to feel sick with the thought that he was infected with HIV.

He came to know about an NGO named *Action for Girijan Development,* which works on the issues related to HIV/AIDS. Also the organization extends support to PLWHAs for treatment and referral services. It provides medicines to the opportunistic infections under *Frontiers Prevention Program (FPP)* funded by *AIDS India Alliance.* When Ramana sought their counseling, he was advised to use condom and eat nutritious food. He asked AGD for a possible job as an outreach worker. They promised that they would place him with a job when an opportunity arises.

As carpentry was not enough to go about life, he started selling fruits on a pushcart. New to the trade, he was earning a paltry sum of Rs. 20 a day. This is the only income for the family. He lives in a thatched hut given to him by the government.

Now Ramana knows the sources of HIV infection and about safer sex practices. He is well informed through doctors in government hospital and activists of NGO. However, he does not know anything about the rights of PLWHAs. So far, he did not face any discrimination, as he did not disclose his status to people outside his family. He seeks support to earn his livelihood, medical care and treatment, from the government, NGOs and the community. He wants to serve his fellow PLWHAs.

Case Study Three

Profile of the Person

Name	:	Satish Naik
Age	:	17
Sex	:	Male
Caste	:	Scheduled Caste
Religion	:	Christian
Marital Status	:	Married
Education	:	Diploma in Mech. Engineering (discontinued)
Place	:	Bodagutta Village, Kothagudem Mandal, Khammam District

Satish was born in 1988 in the Lambada tribe in the Bodagutta Agency area in Kothagudem mandal, Khammam district. He was the fourth child in a family of five brothers and three sisters. His father used to sell coal and wood to get the family going. His mother used to collect coal from railway yards and sell them in the nearby colonies. All his brothers and sisters got married and began to work as labourers for their living. One sister and brother live in Yellandu while the rest stay in Bodagutta.

Satish is only person educated beyond matriculation. One brother and a sister studied up to sixth and seventh classes respectively. Even though the Government offers free education, they were not able to develop interest in pursuing further studies. Satish was interested in further education and found support from a private school teacher in the neighbourhood. He took Diploma degree in Mechanical Engineering at Bhadrachalam Polytechnic College. Although his ambition was to become a teacher he studied Diploma because he cleared the entrance examination for that course.

He stayed in government hostel for three years. Unfortunately, he failed to take the final year examinations as his mother passed away in 2000 suffering from bone cancer. During his stay in hostel, his peers, pushed him into unsafe sex practices.

Early in 2004, he worked in a hotel as a waiter for about one year and during that time he fell in love with a 14 year-old girl and got married to her. When his wife became pregnant, she had to undergo several tests and was tested positive for HIV. Satish decided to go for a test and found that he was also infected. He shared his health status with his wife. Both went for counseling to Kothagudem government hospital. Doctors recommended them to go for Medical Termination of Pregnancy (MTP). But the couple decided to have a child.

They did not want to go to Kothagudem hospital fearing that their health status may become public. A counselor from the Mythri Clinic at Kothagudem referred them to the Khammam Government hospital and also helped them with medicines etc. In December 2004, his wife delivered a baby girl. They did not want to take their daughter for a test. The baby was weak and they could not afford to go for any specific treatment. They were not at all prepared to disclose since they had seen the suffering meted out to four men who died with AIDS in their tanda.

Later, the couple converted to Christianity with a belief that Jesus would save their family from the trauma. They did not look for a job and started preaching Christianity to the people living with HIV/AIDS.

Satish's father passed away at the age of 55 due to brain paralysis. Until then, his father used to support them. After his father's death, they lived on the offerings given by neighbours. At times, even beggars offered food to them respecting them as Christian preachers.

For the whole of a year, Satish suffered from infections such as cough, blisters on the face, occasional vomiting, diarrhea and joint pains. He lost considerable weight and became very weak. When he got into depression, the counselor at the Mythri Clinic consoled him that he would live for another 10 years. It was through the counselor that he gained access to information and medical services. Whenever he got infections, he went to Mythri clinic run by an NGO, *Action for Girijan Development (AGD)*. The doctor at the clinic, appointed by the NGO, treated him and gave medicines including ART. Satish is unaware of voluntary organizations that provide nutritious food.

Satish did not know about HIV/AIDS earlier, now he is better informed. The counselor instilled confidence in him. Though he is aware of safer sex, he did not try as his wife is also infected.

Ever since he got infected with HIV, he underwent a lot of changes in his life. The couple did not disclose their health status to anyone. Hence they have not experienced any stigma from the family or the community as such. However, Satish does not know about the rights of PLWHAs. He appeals to the government and the society including voluntary organizations working for HIV/AIDS to provide them with nutritious food, medical care, employment opportunities and life free from stigma and discrimination.

Case Study Four

Profile of the Person

Name	:	Kamala
Age	:	40 plus
Sex	:	Female
Marital Status	:	Married (widow)
Caste	:	Scheduled Caste
Religion	:	Hindu
Education	:	Illiterate
Place	:	Pedapudi Village, Guntur District

Kamala was born in early 60s in an agricultural labour family. She was the only child to her parents. With the paltry income the parents were earning, they could not send their daughter to school. In the absence of schooling, Kamala did both household and agricultural work. When she was 15 years old, she was married to Nageswara Rao, a close relative who was three years older to her.

Nageswara Rao was also an agricultural labourer. He pulled a rickshaw for transporting agricultural products. He used to earn around Rs. 500 a month. After two years of marriage, Kamala gave birth to a son. A year later, a daughter was also born. Both son and daughter did not go to school. The son worked to contribute to the household income. The daughter did the household work when Kamala was away working in the field.

When she was in her mid-thirties, Kamala lost both parents. Her children grew up and were in their mid twenties. Both were married. Daughter was married off at 14 years and son at 21 years. Kamala's

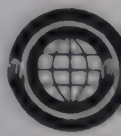
son-in-law and the daughter-in-law both work as agricultural labourers. Kamala has three grand children - two grand sons from the daughter, aged nine and eight years respectively, and an eight year old grand daughter from the son. Her grand children go to school. The parents are keen to send their children go to school so that they can have better jobs.

In the year 2002, Kamala's husband got high fever. It persisted for about a month. From then onwards, he went through all kinds of illness such as vomiting, diarrhea, fever, eye burns etc, frequently. Nageswara Rao used to think that these illnesses were due to strenuous work. Treating them lightly, he took tablets bought from medical shops.

The couple came in contact with an activist named Satyavati of DAWN, an NGO working for women's rights, who resided in the same village. She is a trained ANM. She used to put saline drips and administer injections to village people in times of emergency. Since she was a trained ANM, Nageswara Rao used to go to her, whenever he suffered from infections like cold, fever, cough, blisters etc. She used to give him medicines for common cold and cough.

In 2003, he developed blisters all over his body, and continuous fever that left him bed-ridden. When he went to Satyavati, seeing the severe skin rashes, she suspected if Nageswara Rao was infected with HIV and told him to consult a doctor for a thorough medical examination at Area Hospital, Tenali. Kamala finally took him to a doctor at Tenali, the only nearest town of their village.

After seeing his symptoms, the doctor advised him to have a HIV test and he was found positive. Nageswara Rao had never heard of



HIV/AIDS. He had heard about some of the STIs such as gonorrhea, syphilis, but not of HIV/AIDS. The doctor counseled Nageswara Rao separately and did not talk to his wife. Kamala was unaware of her husband's health status. There after, Nageswara Rao started consuming medicines regularly. When Kamala wanted to know the reason, he brushed off her questions. But when she asked repeatedly, he reprimanded her and told her that she was a woman and it was not her business to know about men. Kamala remained silent. Nageswara Rao practiced unsafe sex with her.

All the while he concealed the truth from Kamala. But as the days passed, he could no longer contain the information from her. He told her that he was suffering from HIV infection and that he would not live long as the infection has no cure. When she asked him how he got it, he said that whenever he was ill he would go to a Registered Medical Practitioner (RMP) at Tenali who was using non-sterilized needles. This he believed was the reason for the infection.

On doctor's advice, Kamala went for HIV test and was found positive. The doctor told her that she got the infection from her husband. In 2004 Kamala's husband suffered from TB, vomiting, diarrhea and became bedridden. Upon the advice of Satyavati, Nageswara Rao joined in a hospital at Tenali as an in-patient and later shifted to Government hospital at Guntur but left immediately due to hostile atmosphere.

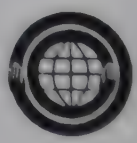
Nageswara Rao has four brothers and two sisters. From his symptoms, they suspected that he was suffering from AIDS. They did not even touch him. In the last days, almost everyone in the village came to know of his health status. When her husband was severely ill, often Kamala had to physically carry him to the doctors, as people

refused to even touch him. Nageswar Rao's son and daughter could not help them financially as they were only agricultural labourers. Occasionally, they would visit their father but see him from a distance and leave. They too feared to touch him.

A month later, Nageswar Rao died at home. After his death, Kamala had to face lot of stigma. Being poor and as a daily wage-worker, she owned a house and nothing else. Neighbours humiliated Kamala, frequently. They whispered behind her back. Most of the villagers stopped inviting her for rituals and celebrations. Even though some people in the neighbourhood invited Kamala for social functions, Kamala never attended, as she thus not want to be ridiculed.

So far, she did not suffer from any health problem. She looked healthy and moved around actively. Every day, she went to work either in fields or at construction sites. She faced no problem on the work front as the *mason* (head of the labourers) gave her sufficient work. He did not show any discrimination as far as work was concerned. Almost every one at the work site knew Kamala as HIV positive, but her co-workers never ill-treated her. However, she maintained distance from them. She never joined her co-workers during lunch breaks, though they invited her. She ate her lunch in isolation and then resumed to work. "Why go there and feel bad when some one said a wrong word?" she argued. This was the coping mechanism she adopted to prevent stigma and discrimination.

She worked for almost 25 days in a month. At present, her health is good so she works. Occasionally, she suffers from diarrhea, which may not be due to HIV infection but because of the contaminated drinking water that is supplied in the villages.



Kamala does not have any resources to sustain her livelihood in long run. If she did not work one day, then she did not have anything to eat the next day. The only property she has is her thatched roof house. Earlier, she was dependant on her husband for her livelihood. But now, she lives on her own.

Her children occasionally visit her and ask about her well being. They spend a couple of hours with her, but they refuse to touch her. They do not allow their children to visit their grandma. Since they work as agricultural labourers, Kamala expects no financial support from them.

Kamala depends on the support of NGOs like DAWN and AIRTDS. She gets moral support from DAWN. The organization refers PLWHAs to doctors. It procures food grains from people to distribute to PLWHAs. Kamala receives antibiotics - four packs - every month towards opportunistic infections, from AIRTDS at Katevaram mandal. It has a care and support program to help people living with HIV/AIDS. However she gets ARV drugs from Government hospital, Tenali.

Prior to the infection, Kamala had no knowledge of HIV/AIDS and other STIs. When doctors at the Government Hospital, Guntur briefed her about HIV/AIDS, STIs, safer sex practices etc she blushed and ran away from the place, without hearing a word of it. She only came to know about it when Satyavati, the fellow woman, briefed her about the symptoms etc. Now, she is aware of HIV/AIDS, routes of transmission, safer sex practices etc. Satyavati helped her in knowing about HIV/AIDS and gain mental strength.

Regardless of the stigma and non-cooperation from one and sundry, she never lost her courage. Lonely, she lives in the hut and goes to work to feed her. She does not expect any monetary support from

her children. The only thing she needs is treatment, medication and moral support. She does not know about the rights of the PLWHAs. She is willing to share her experiences with others. She hopes to receive help from society, Government and the NGOs and to be treated with care and kindness.

Case Study Five

Profile of the Person

Name	:	Kannaih
Age	:	36
Sex	:	Male
Caste	:	Scheduled Caste
Religion	:	Hindu
Marital Status	:	Married
Education	:	Tenth Class
Place	:	Guntur Town, Guntur District

Kannaih was born in 1969 in a village near Guntur town. He has a brother, two years elder to him. By the time Kannaih was born, his father sold all the assets and settled down in Guntur. The father used to sell used jute bags in the wholesale market, after procuring them from retail shops. The earnings were somewhere between Rs. 50 to 60 a day and never exceeded that.

Both the brothers successfully finished their school final. Since his family had no strong financial grounding, Kannaih could not continue his studies further. So he had to look for employment to run the house. Kannaih's brother took up house painting contract work. His brother used to earn Rs. 2500 to 3000 a month. He is married. Kannaih's sister-in-law studied up to intermediate. They have four children - three girls and one boy. All children of Kannaih's brother go to school. Both the brothers live with the parents. Kannaih got married in 1992 to Subhashini. At that time, Kannaih was 23 and his wife was just 18 years. She, unlike his sister-in-law, is illiterate.

As youngsters, when the parents put pressure to find employment, the brothers resorted to strong-arm tactics i.e. bully innocent people in their locality. Thus, they started harassing the residents. They operated with a local goon. They used the money earned for buying alcohol and to meet their personal needs. Kannaih used to practice unsafe sex before his marriage and continued even after the marriage.

In 1994 for the first time, Kannaih was arrested in an attempted murder case. Soon after he was released on bail. He moved out and began living separately with his wife. He continued this life style, of not working, for few more years. Meanwhile, his wife gave birth to two daughters.

In 1997, in an attempt to save the life of his friend, he caused death to a man. He was arrested by the police and was kept in custody for four months. Later, he was released on bail. By the time he was sent to jail, his wife was pregnant and after 10 days of his release, she gave birth to a son.

Since he had no job, it became difficult for him to feed his family. Further, harassment from police too increased. He went to his brother for help and together they started a 'home needs scheme'. It was a scheme in which household gadgets are gifted to the members of the scheme through a lottery.

Early 1998, the police chased Kannaih in connection with the murder case of '97. This time, his brother too was taken into custody. It was proved in the investigation that his brother was also involved in the murder. When the brothers did not return home in the night from police custody, their father had a heart attack. In 1998, Kannaih's father passed away.

On 1 May 1998, Kannaih met with an accident while returning after collection of money from his clients (home needs scheme). He lost blood in the accident. In the hospital, doctors gave him a blood transfusion. Three months later, he suffered from continuous fever and lost weight. One of Kannaih's friends advised him to go for a HIV test and accompanied him to the VCTC. He was found positive. His friend did not tell him anything about the test result and wanted to prepare Kannaih mentally before informing him.

The following week, he arranged a liquor party and invited Kannaih for a drink. After few rounds, his friend engaged Kannaih in a discussion on HIV/AIDS. At the end of the discussion, he told him that he is positive for HIV. Kannaih thought that HIV infection was also like another STD. After the party, he went home and slept.

Next morning, Kannaih woke up to recall what his friend told him. He was frightened and wanted to cry. He heard from a friend that HIV had no cure. He told his wife of being infected with HIV and would die soon. At that time, he did not know the difference between HIV and AIDS. His wife did not know any thing about HIV.

Kannaih and his wife did not go for any counseling. Kannaih had unsafe sex with his wife after being tested HIV positive. Meanwhile in the four years, he did not suffer from any serious illness and bothered not much about it. He became confident and proclaimed to people that he was HIV positive and did no harm to him. He did not suffer from any stigma since he was a known goon in the locality. People maintained a safe distance from him.

In 2002, one day while he was walking around his slum, a person introduced himself as Kumar from Chennai. Kumar told Kannaih that

he was HIV positive person and wished to become his friend. Kannaih was surprised at his outspokenness. They became friends immediately. Kumar counseled Kannaih and took him to a doctor. It was only then that Kannaih came to know the difference between HIV and AIDS, the transmission routes, safer sex etc. From then onwards, he started using condoms while having sex with his wife. He also stopped having extra marital sex.

Kumar started a network named APPU (Association for HIV Positive People's Unity) in 2002. As a pioneer to initiate work for HIV infected people in Guntur district this network became the first of its kind in Guntur. Kannaih became a member of the network. Kumar worked hard to get HIV positive people enrolled in it. He put every effort to persuade them to come out and join the network. With his efforts, several people joined the network and its activities spread across the district. After the initiation, Andhra Pradesh State AIDS Control Society (APSACS) started supporting the network. APPU was active for six months. For some reason, APSACS had to withdraw its support. Then Ramesh Babu took over the management of APPU, and rechristened it as SHIP (Society for HIV Infected People). It was registered in 2003.

In 2004, APSACS resumed its funding to APPU. APPU in the outskirts of Guntur town has presently, a total of 700 members and five staff. Network provides support to PLWHAs with treatment, referral services and counseling. It also distributes nutritious food.

Since 2004, Kannaih has been working as one of the counselors in the network. As far as Kannaih's health is concerned, he is very healthy and moves around actively. He fell ill once in 2004 and developed rashes on his skin. It got cured immediately. He moved

around without any problem ever since he was tested HIV positive. He got his wife tested five times in five years. She was found negative in all those tests. He still does not know about the exact source of his infection - if it was unsafe sexual practice or blood transfusion.

He did not have any sustainable resources to carry out his livelihood. His job as a counselor in the network is the only source of income to him. He earns Rs. 3000 per month as salary for his services, which is just sufficient for his food and accommodation. He donates some money to the local church. He converted into Christianity when he got infected. Before taking up the job as counselor, he underwent training in CHAI and APSACS. He developed linkages with the other voluntary organizations such as World Vision (Nutritious food for children), SEEDS and KMM (doctors referrals), Veera Hanuman and NEEDS (for other support).

He believes that educating people and bringing awareness about the infection in the society can tackle social stigma. He recommends the staff of the NGOs to work with love. He emphasizes the need for sensitivity, concern and care for PLWHAs. He does not know about the rights of the HIV positive people though he works as a counselor.

Case Study Six

Profile of the Person

Name	:	Kavita
Age	:	24 years
Sex	:	Female
Caste	:	Forward Caste
Religion	:	Christianity
Marital Status	:	Married
Education	:	Illiterate
Present Place	:	Hyderabad, Andhra Pradesh

Kavita was born in 1981 in an agricultural labour family in Mulakala Lanka in Sitanagaram Mandal in East Godavari district. She is the second child in the family. Her father and mother aged 63 and 40 work as agricultural labourers. She has an elder brother and a younger brother who are illiterate and work as labourers. Nobody in the family attended school as the family's income was barely sufficient to make both ends meet. At the age of 10, Kavita started working as a labourer to help her family. Her earnings were Rs. 300 per month.

When Kavita was 13, she was married to a tailor named Rambabu, about 12 years older to her. He was a high school drop out. Kavita was his second wife. His first wife deserted him eight years back, a year after their marriage. Kavita left her native village to stay with her husband soon after her marriage. They started living at Rajahmundry.

Kavita delivered a baby boy in 1997. Soon after the delivery, she had some gynecological problems and doctor advised to go for a hysterectomy at a local nursing home in Rajahmundry. She needed blood transfusion for this surgery.

After the surgery, she used to get fevers with headaches and body pains that lasted for three days. These became frequent, over a month. Throughout, she never took the ailments seriously, relying on over the counter medicines. In 2000, the couple moved to Hyderabad for seeking better employment opportunities.

In 2004, Kavita fell ill severely, which lasted for about three months. In the three months, she suffered from consistent fever, vomiting, diarrhea and severe coughs. When she consulted a doctor, he advised her to undergo a thorough medical examination. She found out that she had TB. After four days upon a doctor's advice, she had a HIV screening test and found she was positive as well.

Kavita was shocked when she heard the news. 'How did I get infected with this'. She discussed it with her husband who was also surprised. The doctor who counseled them advised the members of whole family to undergo screening test. Both her husband and her son were tested negative. They believed it to be the transfusion of blood that she had during the hysterectomy infected her with HIV.

She was admitted to the Chest Hospital at Erragadda, Hyderabad as an in-patient for TB. The mental stress of realizing that she was HIV infected made her lose five kgs in just two weeks. She begged her husband to take her home, as she wanted to be at home. He consoled her by saying "Don't worry, we'll live together. Will you leave me if I get AIDS?" She was kept in the hospital for 75 days. She started taking ARV drugs and was soon discharged from the hospital.

These days Kavita looks healthy and maintains an active life. She is cured from TB and to date she has not suffered from any of the opportunistic infections commonly associated with AIDS. She gets her ARV medicines every month from Osmania General Hospital.

Even before she was infected with HIV, she knew about HIV/AIDS as she used to visit her cousin who is a HIV positive. She knew that unsafe sex is one of the causes to spread. She gained knowledge on HIV/AIDS during the counseling sessions at the hospital.

Now, she confidently says that HIV/AIDS is not a contagious disease as other common ailments. She advocates that prevention is best and only way to keep it at bay. She campaigns against unsafe sex, HIV-contaminated blood and needles. She tells people that HIV does not spread through touching, sharing toilets, towels, eating and drinking together. She advises people to adopt safer sex practices by using condoms.

As a precautionary measure, Kavita goes for a TB test for every two months. The couple use condoms. Kavita's husband never allows her to cut vegetables. He fears that she may cut her fingers and contaminate the vegetables with HIV infected blood. He fears of HIV infection through food. Kavita has not revealed about her status. Except her husband, hospital staff and the people in the 'Network for HIV Positive People', where she is presently working as an activist, none of her relatives or neighbours know about it. She fears stigma and discrimination.

Kavita joined 'Network for HIV Positive People" recently as an activist. She earns Rs. 1000 per month and additional travel allowance. Her husband is a tailor and earns Rs. 2000 per month. They have no other resources. They are not able to save from their earnings. The Osmania General Hospital is providing free ARV medicines worth Rs 3000 per month and DARE, an NGO provides nutritious food.

She treats fellow HIV positive people with compassion for the hellish experience they undergo. She urges people to treat them with care

and support. As an activist of the 'Network', she visits hospitals, to give care and support enrolling HIV positive people as members. Kavita keeps a target of enrolling 20 members per month. She is a member of Nrityanjali and DARE - organizations, which are working on issues affecting PLWHAs. She believes that stigma and discrimination can be tackled through awareness and education on massive scale.

She does not know anything about the rights of the HIV infected people. She looks forward to the Government and the NGOs to provide employment and livelihood opportunities. She appeals to the society to treat HIV infected people without discrimination. She urges the staff of NGOs to treat HIV people with absolute dedication and understanding. She urges the medical staff to take extreme care to check blood samples before they transfuse them to the needy.

Case Study Seven

Profile of the Person

Name	:	Mahalakshmi
Age	:	16
Sex	:	Female
Caste	:	Backward Caste
Religion	:	Hindu
Marital Status	:	Married
Education	:	Seventh Class
Present Place	:	Ponnur Town, Guntur District

Mahalakshmi is the eldest among the three children born to Balaji and Rajasri. The family lives in Ponnur town, Guntur district. Mahalakshmi is 16 years old and her two brothers are 12 and 9 years respectively.

She is the brightest among the three. Unfortunately, she could not study beyond seventh class as her family's financial situation did not permit it. Both her parents are illiterates and her brothers are primary school dropouts. Her father is a truck driver. When he got married he was 18 and his wife was just 10. Balaji has two sisters. The elder sister is a widow, has a daughter and the younger one has a son.

Balaji is a truck driver and almost 25 days in a month he is on the road. His income is around Rs. 2000 per month. Mahalakshmi stays at home to help her mother with the household chores. Her mother cooks goodies and sell them. Her brothers also does petty jobs - one works for a provisions shop as an attendant and the other works in a bicycle repair shop. Mahalakshmi sells flowers in the street. Together they earn around Rs. 3000 a month.

In 2002, one day after a quarrel with her mother, Mahalakshmi ran away from home and took refuge in a friend's house. After three days, her mother pleaded her to come back home but Mahalakshmi refused. Two days later, her father's younger sister's son a truck driver, persuaded her to come with him and stay with his parents. Her paternal aunt and uncle were happy to receive her and she stayed there for three months.

During her stay at the paternal aunt's house, her cousin would often come home drunk. One day when Mahalakshmi was fast asleep in her room, her cousin raped her. She was just 13 years old. He threatened that he would kill her in case she disclosed it to anyone. Though she protested on, knowing his violent nature, she remained silent.

Under the pretext of marrying her, he continued making advances regularly. Mahalakshmi obliged out of fear. Her aunt sensed that something was wrong. Mahalakshmi, started missing her periods. She became frequently sick. Her aunt understood that her niece was pregnant. She arranged to send Mahalakshmi back to her parents. When Mahalakshmi returned to her parents, she did not inform her condition to them. Mahalakshmi's mother sensing about on her missing periods took her to a registered medical practitioner for advice. He advised her to terminate the pregnancy immediately. The reason being Mahalakshmi was young and unwed. He also indicated the possibility of Mahalakshmi being infected with HIV and in which case the baby too would have it. Mother and daughter returned home. They discussed with the family and finally decided to terminate the pregnancy. Mahalakshmi was in her fifth month of pregnancy. After the termination, she was tested for HIV and found positive.

Worried about her future Mahalakshmi's parents couldn't find an option but to marry her to her cousin who too was tested positive for HIV. When they learned that her cousin was HIV positive, they felt relieved that he would agree to marry Mahalakshmi. After a month of worrying and thinking, Mahalakshmi's father approached his sister with the marriage proposal. His sister refused the offer. When Balaji refused to give up the marriage proposal his brother-in-law beat him up mercilessly and threw him out of the house. As the fight happened in public, news spread that Mahalakshmi was HIV positive.

From then onwards, Mahalakshmi's cousin started taking advantage of the situation. Whenever and wherever he would meet her, he would whisk her away to fulfill his sexual desires. This continued for long time. Initially, she resisted and fought him. But then his sharp taunts that she was a HIV positive and that no one would marry her, left her that she deserved nothing better. She acquiesced. Under these circumstances having sex with her cousin seemed the only choice.

Meanwhile Mahalakshmi observed that both her parents were frequently falling ill with high fevers. Initially, her mother thought that spending most of the time in front of the fuel stove, affected her breathing. Her father thought that constant exposure to the heat of the engine caused fevers. Taking the symptoms lightly they took medicines bought over the counter.

One day, her father fell unconscious when his truck reached Kavali in Nellore district. He left the truck in the custody of the cleaner and went to his relative's house. His relative knowing him as a truck driver rushed him to a doctor. When the doctor advised him for test, he was found HIV positive. On coming back home he sent his wife for test. She was also tested positive. Shaken by this turn of events, the entire

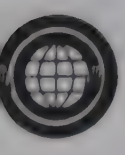
family went to Chennai for a check up where they had a variety of tests and got ARV medicines for a month.

Being young, healthy and petite Mahalakshmi did not experience poor health. On the other hand, her parents fell ill every ten days. They got high fevers, vomiting and diarrhea. The family spent most of the income on medicines. Her father went to Chennai Sanatorium once every three or four months to get medicines. He was on medication for the last two years.

Mahalakshmi's parents had no sustainable means of livelihood. They built a thatched roof on a *patta* land given by the state government. Though they get ARV from Chennai, they spent a big chunk of their income on buying antibiotics for opportunistic infections and barely manage to buy normal food. Since most of the time Balaji is ill, he does not get work. When he is not sick in bed, he goes on duty and earns some money.

Balaji seldom goes out for the fear of stigma and discrimination even though he knows that many of his fellow truck drivers were also tested HIV positive. He does not go to his employer; his cleaner boy comes with the truck and calls him for duty.

Mahalakshmi's mother does not venture out as well. Neighbours talk to them on general terms but do not share any relationship with them. She observed that people talk sarcastically behind them. She is not invited to attend any rituals or celebrations. The youngsters residing at the corner of the street bully her in chorus "*Puliraja is coming" (*a popular TV advertisement "Will Puliraja get AIDS?.....) when she goes to sell flowers in the street. The family is learning to cope up with the stigma and discrimination with a "don't-give-a-damn" attitude.



The infected family never knew much about HIV/AIDS. Balaji who had been infected with STDs got cured on earlier occasions. But he did not hear much about HIV/AIDS. The counseling session at the Chennai Sanatorium made him aware of the difference between HIV and AIDS. He became aware of contracting of the infection, and its prevention. Mahalakshmi's mother describes AIDS as a killer disease, which has no cure. She is indeed, able to explain the routes of transmission, preventive measures etc. She knows that it is not contagious.

Mahalakshmi knows about HIV/AIDS. She is able to explain the symptoms of HIV/AIDS, preventive measures, and its spread, etc. Most of the information is gained through counseling. Some more information is accumulated through magazines, TV and friends. Mahalakshmi has a desire to work for HIV positive people. She says she will join some organization as an activist sometime in future and help the infected people. She wishes to share her experience with others so that they don't suffer her way. At present, she is with DAWN that offers referral services and provides nutritious food.

Balaji's wife has no complaints about her husband and feels that ridicule is not the solution. Mahalakshmi's family is concerned about the PLWHAs and wants the community to accept them without stigma and discrimination. However, they do not know about the rights of PLWHAs. They opine that the best way to tackle stigma is to educate people on HIV/AIDS. They hope that the Government and the NGOs would provide, nutritious food, medicines and suitable employment.

Case Study Eight

Profile of the Person

Name	:	Suguna
Age	:	20 years
Sex	:	Female
Caste	:	Scheduled Caste
Religion	:	Hindu
Marital Status	:	Married
Education	:	Illiterate
Present Place	:	Rekkamanu Village, Kadiri Mandal, Anantapur District

Suguna was born in 1985 in Vempally village in Kadapa district. Her parents were agricultural labourers. Suguna's mother was married at the age of 10 and gave birth to a female child, at the age of 13. Two years later a son was born and Suguna was the last one. Her father died when Suguna was barely three-months old. When Suguna was a year old, much against the wishes of her family, her mother involved with another man.

They moved to Rekkamanu, a village situated near Kadiri town in Anantapur district. Suguna was admitted to the local school and studied up to seventh standard and couldn't continue further as the school had up to seventh class only. At this point in life, she started working as a shepherd, taking the sheep of a neighbouring farmer for grazing to the fields, and bring them back in the evening. Her earnings were Rs. 20 a day.

Initially, Suguna's stepfather used to work as an agricultural labourer. Severe drought conditions in the year 1998, left him without any work in agriculture. He and his wife had to resort to begging. They would beg on the streets of Hyderabad, come back to Rekkamanu, give money to Suguna and resume the same. Suguna was left alone at home.

Suguna had a friend Ramaswamy Naik aged 20. He would often ask her if she liked to better her life. Thrilled by the prospect of changing her life, she took the support of Naik. He told her "I have an aunt in Pune in the state of Maharashtra. She has a small kid and is looking for some one to look after her kid. You go to their house. They will give you food, clothes and shelter. You don't have to worry about any thing. You can study further there".

Hesitant, Suguna took it up. Naik begged her not to reveal to anyone. Suguna told her neighbours that her parents were ill in Hyderabad and she was going to see them. Along with Naik she reached Cherlopalli (near Rayachoti, Kadapa) and stayed at a friend's house for two days. Then Naik returned back to the village assuring her that his friend would take her to Pune.

The appointed friend took Suguna and looked after her well during the journey. When they reached Pune, he took her to a two-storied building and introduced her to a middle aged woman supposedly Naik's aunt. They spoke to each other in Hindi, which Suguna did not understand. He left her in the care of the lady and returned back. Three days passed and Suguna found that she was looked after very well. Suguna also noticed that there were some more girls who were from her village. When Suguna inquired about the work they were supposed to do, one of the girls pulled her aside and reprimanded her for coming

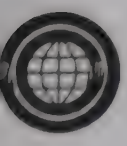
to a place like this. She told Suguna that it is not a nice place to be in. She also told her that all the girls were brought here on the pretext of a decent job.

Suguna was aghast and informed the lady that she didn't want to stay and wished to return to her native village. The lady confronted her with a startling news that she had paid Rs. 18000 to the person who accompanied her and unless the money was paid back she would not be allowed to leave.

Suguna was devastated. She protested, sobbed and even tried to escape but all in vain. A week passed by, the lady began torturing Suguna to entertain customers. Unable to find a way out, Suguna had to give in. From that day onwards, Suguna's life was spent entertaining customers. Her *madam* used to charge Rs.60 per customer for time spent with Suguna and Rs. 2000 if they spent the night. Suguna did not receive a penny of this money. She merely received food, shelter, and clothes and occasionally was allowed to go out with the customers. She spent two years, however at Pune.

Meanwhile, her parents returned back and began searching for Suguna, but could not trace her. They finally reported the matter to the village Sarpanch and the police. The police tried their best but could not locate Suguna.

In the course of investigation, Suguna's parents discovered that she had spent a lot of time with Ramaswamy Naik. When questioned, he bluffed and feigned ignorance. They sensed that something was amiss and reported the matter to the police. When the police repeatedly questioned him, he finally told them the story. With this crucial information, the local police contacted the counterparts in

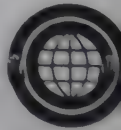


Pune. The Pune police raided the place where the girls were put up and freed all girls. Suguna walked out of the place without a penny in hand.

In 2000, she returned home escorted by the police. As she had acquired some knowledge on STDs and HIV/AIDS during her stay in Pune, Suguna took a precautionary step to get her screened for HIV. She was tested positive. When she approached the counseling chamber, the doctor consoled and assured her that she had nothing to worry about. He assured her that she could live another 20 years, if she ate nutritious food and took proper medicines.

Having identified her as HIV infected, a voluntary organization 'Sthree' employed her as an outreach worker for HIV/AIDS work. Suguna did not know much about HIV/AIDS earlier. The doctor, whom she used to go for check ups, in Pune, had informed her about various sexually transmitted infections including HIV and briefed her about preventive measures. At 'Sthree' she attended several meetings and training programs and got empowered on matters related to HIV/AIDS. Now she knows about routes of infection, safer sex practices, preventive methods etc. She also became aware of the difference between STDs and HIV, HIV and AIDS. Trained through UNICEF sponsored programme, she is an activist at 'Sthree'.

While she was working for 'Sthree' Suguna married an activist colleague. She became pregnant in 2004. When her husband was tested, he was found negative. She left the job at 'Sthree' in her advanced stage of pregnancy. Her husband also quit his job. Suguna and her husband became dependent on whatever Suguna's parents earned through begging. A baby girl was born in July 2004. Very recently, Suguna's husband found a petty job. The couple has no



assets except for a government allotted house. She does not receive any kind of assistance nor did she approach any organization for assistance.

So far, Suguna has not suffered from any health problem. Her one-year old baby is yet to be tested. Suguna has not disclosed to anybody in the village that she is a HIV positive for the fear of stigma and discrimination. The people in the village knew that she was trafficked to Pune. Her villagers never heckled her. The women in the neighbourhood invited her to all community events. Suguna hesitates to tell people. "AIDS is a different thing. The moment people hear about it, they recoil in horror" she says. She is ready to share her experiences with strangers.

Suguna needs a job, nutritious food and ARV drugs. She does not know about the rights of the people living with HIV/AIDS. She thinks that education and raising awareness levels are the best ways to tackle stigma and discrimination that HIV/AIDS create. She hopes that the state and the NGOs can come forward to provide employment opportunities and medication. She shows concerns at fellow HIV infected people. "Maybe, they are suffering for no fault of theirs. It's time that we provided them care and support". She urges the staff of NGOs to treat HIV infected people with compassion, commitment and devotion, and not as a mere job.

Case Study Nine

Profile of the Person

Name	:	Gowri
Age	:	9 years
Sex	:	Female
Caste	:	Backward Caste
Religion	:	Hindu
Marital Status	:	Unmarried
Education	:	Fifth Class (studying)
Present Place	:	Madakasira, Anantapur District

The case revolves around Gowri, a little girl. She is the protagonist of this saga and is too young to tell us her story. Instead, it is her grandmother who spoke on behalf of Gowri.

"I am Gowri's grand mother, her mother's mother. Gowri stays with my husband and me. We all live in Jekkapalli, a remote village bordering Karnataka state. Geographically our village comes under Madakasira mandal in Anantapur district. Madakasira is the nearest town. The district headquarters, Anantapur town, is as far as 100 plus kilometers.

I feel extremely sad and remorseful whenever I set eyes on the hapless girl who looks stoically at the people who visit us to know the details of our family. At that tender age, she is unable to understand what struck our family and the predicament she is in.

Let me unravel the story of our family first. My husband is a small farmer with a couple of acres of land. Our family is the poorest and the family income is barely sufficient to make both ends meet. I have

three daughters and a son. All are married and settled elsewhere. Gowri's mother was my second daughter. My son-in-law hails from G.N. Palem, also happens to be a close relative. He studied up to school final. My daughter got married in 1990 and she was only 14 then. He used to cultivate land inherited from his parents and feed the family.

My son-in-law used to fall sick frequently before marriage. Since all his family members are very lean and suffer from various illnesses every time, we thought that this is quite normal in their family. So we went ahead with the marriage.

The couple had four children: three sons and a daughter and Gowri is the third. The other three died. The first son died after nine days of delivery; second son after one and half years; Gowri survived; the fourth child, again a son, also died five weeks after delivery. All the children suffered from illnesses such as fever, diarrhea, rashes on the skin etc. Since ours is a remote village, all deliveries were performed by a local untrained midwife. This is the usual practice in the village.

When Parvathi was five years and her mother was pregnant with a fourth child Gowri's father died with a strange illness. All the time he suffered from fever, vomiting, diarrhea, severe cough and rashes on skin. Family members thought that he died of some illness, probably TB.

When Gowri's mother got administered with first of two antenatal doses of TT injection, during her fourth month of pregnancy, she got high fever. It was perceived that the TT injection caused fever. But, there were fluctuations in her temperature and the fever continued the entire period of her pregnancy.

With the delivery of the fourth child, Gouri's mother became weak, turned jet black, suffered from rashes, diarrhea and hair loss. She gave birth to a baby boy in a state of delirium. I still did not know what struck my daughter. Ten days after the delivery, she realized that she had delivered a baby boy.

When word spread in the village that my daughter was showing signs of AIDS and that her husband also died with AIDS, an activist, from MYRADA – Mysore Rural Reconstruction And Development Agency (an NGO, based in Karnataka working in neighbouring villages of Andhra Pradesh), came asking for my daughter.

Having identified the symptoms and about the family history, the activist from MYRADA advised me to take her for an HIV/AIDS test. She was found positive. The activist told me that my daughter might have been infected through her husband and advised me to treat her without stigma and discrimination.

Earlier, I did not know a thing about HIV/AIDS. We had never heard of it before. The activist counseled my daughter and also referred CRSD for some assistance.

I went to my son-in-law's parent's house and chided them for being cheated. They stated that they were not aware prior to the marriage. They said had they known before, they would not have agreed to the marriage proposal. They said that they had known about it after the marriage when he was sent for medical examination to Anantapur for his illnesses. They told me that they did not disclose it for the fear of stigma.

There after, they severed all relationships with us and mercilessly abandoned the little girl Gowri. They even refused to give her, her

father's inheritance. I also did not like the idea of leaving Gowri at their house. I decided that she would live with us as long as she survives. I came back home and started taking care of my bedridden daughter with greater tenderness. However, she died in 2001, having spent a year in delirium.

Gowri is the only child who survived in her family. My husband and I take care of Gowri's every need. So far I have not taken Gowri for a test since we are not inclined to know. The nearest testing facility is located 150 kms away. Anyway for us, it doesn't matter. The only thing that matters is that she is our child and needs care and comfort.

When Gowri turned nine, she began to get sick. Occasionally, she gets cold and fever, suffers from loose stools, pains in the joints, and boils on the skin. I don't allow her to do heavy work. I treat her like a glass doll and like my own daughter.

Of late, Centre for Rural Studies and Development (CRSD) an NGO in Anantapur is taking care of some of the needs of Gowri. She is studying fifth standard in the bridge school that the organization is running at Madakasira. CRSD is providing nutritious food and referral services. We are searching for Government Hospital for medicines and treatment.

The counselors/activists at CRSD have enlightened me on the issues related to HIV/AIDS such as routes of spread, opportunistic infections, methods of prevention etc. In the village, people don't discriminate against us. She goes to the neighbourhood to play with children and nobody objects to this.

I feel depressed about her future, who will look after her? We own a few acres of land and a house in the village. The land is not a

sustainable resource as it is not fertile. I don't know anything about the rights of the people living with HIV/AIDS. She continues, "the effect of HIV infection has been disastrous on our family. We lost our daughter, son-in-law and their three children. I urge the community, the state and other organizations to treat HIV positive people with care. They should not be stigmatised or discriminated. Since the infection hampers livelihood prospects to the HIV infected people, the state and the organizations should create employment opportunities for them. I strongly believe that the stigma and the discrimination can be tackled through education and awareness on HIV/AIDS. I appeal the state government and the NGOs to spread the message across so that people become aware and prevent the infection".

Case Study Ten

Profile of the Person

Name	:	Mallesh
Age	:	40
Sex	:	Male
Caste	:	Scheduled Caste
Religion	:	Christianity
Marital Status	:	Married
Education	:	Seventh Class
Present Place	:	Uppalapadu Village, Guntur District

Mallesh works as an attendant in the office of the Regional Director - Medical & Health, Guntur. He got married to Udayakumari in 1990, when Mallesh was nearing thirties and Udayakumari was in her early twenties. Udayakumari studied up to tenth class while Mallesh, studied up to seventh class. After two years of their marriage in 1992, the couple were blessed with twin children. They thanked Christ for blessing them with - a male and a female child. They distributed sweets among friends, relatives and neighbours. The children were named as Jagadish and Mamta. Two years later, another daughter Hadasa was born. Jagadish was happy to have two sisters.

The couple, themselves not being highly educated, wanted to fulfill their aspiration through their children. Nevertheless, the children Jagadish and Mamta are studying seventh class and Hadasa in fifth class respectively.

Mallesh had premarital sex and the habit continued even after marriage especially when his wife was in the advanced stages of

pregnancy. Udayakumari was aware of his extra marital affairs. She used to plead him to reform himself but he turned a deaf ear on her pleas.

From early 1994, Mallesh's son, Jagadish, i.e. from three years, began falling ill. He used to suffer continuously from severe blood vomiting and diarrhea. Mallesh took his son to a local nursing home and got him admitted as an in-patient. He was put under medication. The doctors informed Mallesh that his son was anemic and advised for a blood transfusion. Since Mallesh's and his son's blood groups are the same, he donated his blood. The medical staff did not test the blood for possible infections. After a week, the boy was completely cured and was discharged from the hospital. Everybody at home felt happy.

Later that year, Mallesh fell ill. He suffered from continuous fever followed by severe cough, mild paralysis, vomiting, and diarrhea. Mallesh suspected that, working in the health department, he might have been attacked of TB. He immediately went to a chest specialist, at Guntur. There he was detected of having TB. The doctor advised him to go for a HIV test. He was tested positive. Subsequently, upon the doctors' advice, the whole family was tested. His son Jagadish was found positive. This shocked the family.

Initially, his wife did not know much about HIV/AIDS. She thought that HIV/AIDS was like a fever. But, after learning more through television advertisements and other literature that it had no cure, she felt numb and powerless. She shuddered to think about the future of her little son, Jagadish.

Mallesh blamed himself. "What does a father usually do for his children? He bestows his children with property or money. But what did I do? I gave him an infection for which he will suffer all life".

With people coming to know Mallesh did not suffer any discrimination. There were no whispers behind his back at the office. His colleagues behaved as they were always with him. Neighbours let Jagadish and his two sisters play with their children. They invite Udayakumari to ceremonies and celebrations.

The family has a small house of their own. Except for the paltry income that Mallesh earns, the family has no other income. Now, they take the burden of buying nutritious food and medicine for - Mallesh and Jagdish.

Ever since Mallesh was tested positive for HIV, he started practicing safer sex with his wife. Udayakumari got tested twice and found negative. She has no hatred towards her husband. She treats him with care. "Whatever happened has happened. No one can rewrite the fate", she feels.

Presently, two NGOs are assisting the family. Udayakumari has been a member in World Vision since two years and in SHIP (Society for HIV Infected People) for the past year. World Vision provides nutritious food – Rice, Ragi, oils etc. SHIP provides medication (antibiotics only - for opportunistic infections) and grains occasionally. Udayakumari, along with her son, attends the meetings of these organizations but her husband does not as he does not want "unnecessary exposure".

Udayakumari alleges that the doctors never told her anything about HIV/AIDS. She accused the doctors that they did not counsel her about her husband. They informed her husband about his infection and never uttered, a word as to what precautions were to be taken. She says that she acquired full knowledge about HIV/AIDS only after she started attending the meetings of the organizations working for

the positive people. Mallesh too did not know much about it. Post-counseling helped him a lot. But he does not share the knowledge with his wife.

As far as their health is concerned, Mallesh and his son often fall ill due to opportunistic infections. Mallesh often suffers from fever, vomiting, and diarrhea whereas his son gets skin rashes on the neck and blisters at the nostrils. He also gets foul smelling boils on his head. They collect ARV drugs from the government hospital, Guntur.

The teachers and the children at the school do not know about Jagadish's status. Jagadish fears the reprimand of his teachers whenever he becomes sick. He naively asks his mother –"Amma, why don't you tell my class teacher that I am infected HIV positive so that I don't have to go to school? Otherwise my teacher will cane me" – When Udayakumari hears this, she breaks down.

Mallesh does not really know about rights of the HIV positive people. He greatly looks forward for care and support, nutritious food and medicines from organizations working for the HIV positive people.

Case Study Eleven

Profile of the Person

Name	:	Venkatamma
Age	:	20 years
Sex	:	Female
Caste	:	Scheduled Tribe
Religion	:	Hindu
Marital Status	:	Married
Education	:	Fifth Class
Present Place	:	Motukupalli Village, Kadri Mandal, Anantapur District

Venkatamma was born in 1985 at the village Peddur (near Bangalore) in Karanataka state in a family of agricultural labourers. She is the only child in the family. The parents of Venkatamma are illiterates. Venkatamma did not study beyond fifth class because of financial constraints. She remained at home and helped her mother doing household chores.

At the age of 11, her parents married her off to a person living at Motukupalli village near Kadiri. Parents of Venkatamma have a distant relation with her husband's family. Her husband is not well educated and does petty jobs. After marriage, Venkatamma left her maternal family at Peddur and settled down with her husband in Motukupalli village.

Nine months after the marriage when she was barely 12 years of age, Venkatamma gave birth to a son in 1997. The couple with the child spent their time happily for three years.

After four years of marriage, Venkatamma's husband got into extramarital affair for a year and finally abandoned his wife and child. Venkatamma's father took her and the child to his house at Peddur. Four years went by. In the four years, her husband never visited her once. Throughout this ordeal, Venkatamma's in-laws were concerned about her life. But they could not change their son's mind. Yet, they persisted. At every opportunity, they reminded their son of his responsibilities.

Venkatamma's husband came back in 2004 and took his wife and son back to Motukupalli. One day, he came down with a terrible fever along with vomiting and diarrhea. In a month, the fever revisited him and a few more times. Her father advised her to take him to a doctor in Bangalore whom he knew very well. Since her native village Peddur is very near to Bangalore, the couple and their son went to her parental house and from there went to the doctor at Bangalore.

The doctor examined him thoroughly and advised to go for a HIV screening test. The test was positive. Then the doctor counseled them and advised the other family members also to go for the test. Venkatamma tested positive and the son negative.

Her husband was in tears as soon as the news broke out and he begged her to forgive him. He said he might have contracted due to unsafe sex outside. He was under medication for two months and recuperated. In those two months, the family stayed at Peddur. During the counseling session, the doctor briefed Venkatamma and her husband about the symptoms of HIV and its dos and don'ts. He assured them that there was nothing to worry and they would live long if they had a nutritious diet and ARV drugs.

With proper medication he was healthy again. The couple returned to Motukupalli. A few months passed. Again, he left Venkatamma and returned three months later and was very severely ill. She took him to Bangalore again. This time her husband did not respond to treatment and he died two months after.

From then onwards, Venkatamma has been living separately in a hut with her eight year old son. When her husband died, she was thrown out of the her house. She refused to stay with her parents. She lives by working on construction sites. Her son goes to work with her.

So far, Venkatamma has not suffered from any opportunistic infections. She is healthy and active. The HIV infection brought social and economic changes in her life. She moves around with HIV infected women in her village. (The other infected women belong to Sugali tribe and are victims of trafficking). No one in the village invites her to community functions and nobody drinks or eats at her house. She says she does not care about the social ostracization.

She copes with the stigma and discrimination by withdrawing into her own world. The post-counseling at Bangalore helped Venkatamma gain knowledge about HIV/AIDS. Now, she is able to describe the symptoms, the difference between HIV and AIDS, the routes of spread, prevention measures etc. She laments that her needs are not being met properly. She needs a regular job, nutritious food and ARV drugs. She fears that if she discloses about her infection she may be thrown out of work. An NGO called REDS (Rural and Environment Development Society) based at Kadiri is offering referral services. She does not know any thing about the rights of the HIV infected people. She expresses concern for PLWHAs and urges people to accept them with care and humanness.

Annexure 1

Questions Asked

Family

- Personal details of PLWHAs (age, sex, location, area, caste, religion, class, occupation, income, education, present health condition, dependency, position in the family and social status etc.)
- Dependency on the spouses/family members/others and relationship with parents
- Rights within their homes, in-laws and within their natal homes

Knowledge on HIV/AIDS

- How and when did they become aware of the infection?
- The awareness levels of HIV/AIDS before and after being infected
- How did they internalize HIV/AIDS?
- Did counseling help them in any manner?
- Awareness on the child bearing levels/abilities and vulnerability to HIV/AIDS and other STDs
- Do they become members of HIV positive network/with other networks?
- How knowledgeable are they about their rights?
- What do people think about safer sex (sex with a condom)?

Economics

- Changes experienced in the status of their livelihoods, employment, income, survival, family c1are, community support, etc.
- Economic support from the family

- Changes, if any, in economic status; in the nature of employment and social security?
- Access to health/medical care and treatment, drugs, basic services like nutritious food, etc

Stigma and Discrimination

- How did their environment change? Changes in – family members including children, friends, civil society organizations, health workers, government organizations, employers and individuals with integral relationship to people living with HIV/AIDS responded? What advice was given?
- How their lives changed after they came to know about the infection?
- How would they tackle discrimination?
- The different kinds of coping mechanisms used by women, men, girls and boys? Resources/support to survive in the long run

Gender Issues

- Any gender bias with regard to awareness/knowledge and information
- Role of women to negotiate powers about sex within marriage and outside marriage
- If any stigma, discrimination, violence experienced and its consequences on the PLWHAs and their family members (also if the experience is different for men and women)
- Any access to non-written forms of information which prevents both men and women from becoming aware on HIV/AIDS
- Are particular needs of women's/men's and concerns addressed appropriately and adequately? Are their capacities and skills recognized?

Other Relevant Information

- What is the advice they have for the NGO staff?
- Their involvement in preventive/curative/counseling/awareness activities of Government and NGOs
- What help/support do they seek from state/civil society organizations?
- If they prefer absolute confidentiality or wish to share their experiences with others?
- Any other relevant information

ENCOUNTERING HIV/AIDS

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